

PARENTING &
DISABILITIES

ABIDING
IN GOD'S
PRESENCE

31-DAY DEVOTIONALS FOR LIFE

STEPHANIE O. HUBACH

Stephanie writes with joy and vigor as she exhorts readers to enter the world of the exceptional. Your heart will melt and be lifted as you encounter her beautifully and eloquently written personal stories, struggles, and victories. Her devotionals are enjoyable, provocative, and compelling. *Parenting & Disabilities* brings readers to a deeper understanding of the beauty and blessing of having a child who is exceptional and to the God who knows each child and family completely. Even more, Stephanie invites her readers to embrace the journey and process in the presence of an almighty and faithful God.

—**Suzanne R. Bates**, Assistant Professor of Counseling, Covenant Theological Seminary

The words “Dad showed up” in the introduction arrested me, and I was flooded with the presence of God’s love. As a parent of atypical children with unique neurological wiring and chromosomal content, I struggle daily with feeling totally disabled as a dad. The eight gifts of grace in this devotional are theologically grounded and written in a highly practical and accessible style. This book helped me to engage and receive from God what I need to parent my children in his wisdom and strength rather than staying stuck in my own inadequacies. God’s ability to father me as I father my own children contains much mystery—but that is often where God meets us and confirms by his Holy Spirit that we are his and that God. Is. With. Us. I highly recommend this book as a lifeline for parents who are too often drowning in their own sense of inadequacy; it offers a pathway back to the Father’s heart, where we receive his adequacies and excellencies!

—**Thomas L. Boehm**, Ann Haskins Assistant Professor of Special Education, Coordinator of Ann Haskins Special Education Program, Director of Wheaton Center for Faith and Disability, Wheaton College

Parents of children with disabilities often struggle to believe that God is for them and with them. Stephanie Hubach has lived this

struggle. Through biblical reflection and poignant storytelling from her own experiences as a mother of a son with Down syndrome, she explains how God manifests his presence through eight gifts of grace that strengthen and encourage parents on the long journey of shepherding their exceptional children. Full of wisdom gleaned from the intersection of Scripture and life, Stephanie guides parents, with hope, to look to the One from whom their help ultimately comes.

—**Michael R. Emlet**, Dean of Faculty and Counselor, Christian Counseling & Educational Foundation; Author, *Saints, Sufferers, and Sinners*

This little devotional is a wonderful gift to any parent or family impacted by disability. *Parenting & Disabilities* is Christ's hope and comfort made available in a form filled with encouragement for loved ones of children and adults with intellectual or developmental disabilities.

For parents and caregivers of children and adults with disabilities, Stephanie Hubach represents a wise counselor with a deep understanding of Scripture as well as a good friend who has walked in their shoes all rolled into one. Learning to abide in God's presence is a great blessing to anyone on the special-needs journey who loves God and cherishes his wisdom and peace. Stephanie Hubach has the gift of being able to pull from Scripture and explain it in a way that cuts right to the heart of what our families impacted by disability need.

—**Stephen Grcevich**, MD, President and Founder, Key Ministry; Author, *Mental Health and the Church*

Stephanie Hubach's depth, practical wisdom, and gravitas as a veteran parent, ministry leader, and counselor-theologian to families affected by disability are matchless. *Parenting & Disabilities* offers a gracious deep dive into the core, universal issues that rattle the faith of parents, in order to free us. Required reading for

parents committed to growing through—rather than despite—our uncommon journey.

—**Diane Dokko Kim**, Disability Ministry Consultant; Author, *Unbroken Faith*

When God has gifted you with a child with disabilities, it can be, at times, wearisome. You are never quite an empty nester, and retirement—well, maybe not. The only thing that can sustain you in this weariness is faith. Rock-bottom faith that allows you to put one foot in front of the other, to keep showing up for life with a smile on your face—that kind of faith. Stephanie Hubach’s devotional is aimed right at building your faith so that you can do yet one more day of “faith working through love.” So thank you, Steph, for encouraging my faith and the faith of many other parents who so desperately know that they need their faith built!

—**Paul E. Miller**, Executive Director, seeJesus; Author, *A Praying Life*

In *Parenting & Disabilities*, Stephanie reminds parents who are raising children with disabilities how the gospel changes everything! From her own experiences of raising a son with Down syndrome, she shares many stories that I can relate to as a special-needs sibling and mom. Then she uses those experiences to point us to Christ and his work on our behalf. This gospel-centered book will encourage and refine other parents like us on the unexpected journey of special-needs parenting.

—**Sandra Peoples**, Special Needs Ministry Consultant, Southern Baptist of Texas Convention

Devotional books are crowding the store shelves these days, but you hold in your hands a truly exceptional one. While many monthlong devotionals might skate the surface, *Parenting & Disabilities* breaks the ice and goes deep. And when you parent a child with a disability, your soul thrives on deep. My friend Stephanie Hubach has packed a punch of tough theology and wise biblical

counseling onto each page of this remarkable new work, all the while making it oh so easy to read. If you are a special-needs parent who is thirsting for spiritual renewal and refreshment, and if you need guidance concerning your child's disability, this is a treasure you won't want to pass by. Spend time every day with Stephanie in her powerful new book, and you will be enriched!

—**Joni Eareckson Tada**, Founder, Joni and Friends International Disability Center

PARENTING &
DISABILITIES

31-DAY DEVOTIONALS FOR LIFE

A Series

DEEPAK REJU

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IN GOD'S
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STEPHANIE O. HUBACH



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With deepest love for my faithful husband, Fred—who loves me unconditionally, encourages me regularly, points me to Jesus consistently, and continues to partner with me in this remarkable, transformative adventure called parenting. Fred, you are the best.

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How to Nourish Your Soul

A LITTLE BIT every day can do great good for your soul.

I read the Bible to my kids during breakfast. I don't read a lot. Maybe just a few verses. But I work hard to do it every weekday.

My wife and I pray for one of our children, a different child each night, before we go to bed. We usually take just a few minutes. We don't pray lengthy, expansive prayers. But we try to do this most every night.

Although they don't take long, these practices are edifying, hopeful, and effective.

This devotional is just the same. Each entry is short. Just a few tasty morsels of Scripture to nourish your hungry soul. Read it on the subway or the bus on the way to work. Read it with a friend or a spouse every night at dinner. Make it a part of each day for thirty-one days, and it will do you great good.

Why is that?

We start with Scripture. God's Word is powerful. Used by the Holy Spirit, it turns the hearts of kings, brings comfort to the lowly, and gives spiritual sight to the blind. It transforms lives and turns them upside down. We know that the Bible is God's very own words, so we read and study it to know God himself.

Our study of Scripture is practical. Theology should change how we live. It's crucial to connect the Word with your struggles. Often, as you read this devotional, you'll see the word *you* because Stephanie speaks directly to you, the reader. Each reading contains at least one reflection question and practical suggestion. You'll get much more from this experience if you answer the questions and do the practical exercises. Don't skip them. Do them for the sake of your own soul.

Our study of Scripture is worshipful. There are so many challenges when you live as the parent of a child with disabilities. Does the Bible speak to your experiences? It resoundingly does. While others may marginalize your child, God doesn't. The Lord values and delights in your child. He helps you with your fears, grief, shame, and temptations. He sends Jesus, who is your unrelenting Advocate. As you constantly advocate for your child, Jesus sympathizes with your weakness and prays for you before his heavenly Father.

So yes, the Bible has much to say about parenting a child with disabilities. In this wonderful meditation, Stephanie will point you to Christ as your all-sufficient Savior. That in turn will leave you with no choice—it'll inspire you to worship. There will be a day when there are no more tears, no more obstacles to your child's needs, no more concerns about your child's future. You, your spouse, and your child will live in and enjoy God's presence for all eternity.

If you find this devotional helpful (and I trust that you will!), reread it in different seasons of your life. It will help to remind you of God's goodness and power and promises, both in good seasons and in bad. So work through it this coming month, and then come back to it a year from now to remind yourself about what God and the gospel teach us about parenting.

This devotional will give you strength for your journey. After you finish reading (and rereading) it, if you want more, you'll see resources listed at the end of the book. Buy them and make good use of them.

Are you ready? Let's begin.

Deepak Reju

Introduction

I'M SO GLAD you picked up this book. Truly, I am. If you're new to parenting in "disability world," you may be both curious and a bit nervous about reading this. If you are a seasoned veteran parent of an adult child with disabilities, you may be a bit skeptical—perhaps even jaded. I get that. Honestly, I've been disappointed by many volumes written on parenting due to their frequent emphasis on how-to. You probably know the types of books—they feel like parenting cookbooks. Put in the right ingredients, set the family oven at the correct temperature, and voilà! Out comes the type of child you were always hoping to raise.

If you're parenting a child with exceptionalities, however, you are already caring for a child who is likely quite different than you initially expected. Parents like us don't need another how-to book. We need a "who-to" book, because the real question is this: *In the face of all the unique challenges of parenting children (or adult children) with developmental disabilities, whom do we turn to?* Whom do we go to when we encounter sleepless nights, difficult behaviors, or medical trauma?

The goal of this devotional is to turn our focus to Christ—the one who is always with us and always for us. We don't need to wait for God to show up, because he is already present. What we need is to recognize his presence and to abide in it.

God with Us

My dad is a great guy. And he is also an engineer and an introvert—so he doesn't initiate a lot of people time unless he needs to. So when I was in college and my dad called me to ask, "Can I take you out to lunch?" it was a big deal.

I was a freshman at the time, living forty-five minutes from home. I had not dated a lot in high school, but now I suddenly found myself casually dating three guys *at one time* and didn't really know how to handle it all. All three were off campus in Baltimore. One was rebounding from his longtime girlfriend. (I knew what to do with that one.) The other two were, curiously enough, both named Charles. Charles Smith. And Charles Jones. That's the truth.

Well, back in the day, there was only one pay phone on the entire dorm floor for fifty young women. If someone received a call, they bellowed down the hall, "Steph!! It's for you!!" If you weren't in, then they would write a message on your erasable board on your room door. This was all well and good enough . . . until your friends left the message that Charles or Charlie or Chuck had called. Imploring them for more details, I'd beg, "What was the *last* name?" When the response was "I don't know. Smith? Or Jones?" I'd pull my hair, saying, "It matters! Which one was it? *Smith* or *Jones*???"

This communication crisis stressed me out. So my dad came up to give me some advice. Honestly, I don't remember what he told me. All I know is that he came. Dad showed up.

Now, if it is a big deal when my earthly dad shows up, then *how much more* of a big deal is it when my heavenly Father does?

Most of us limit the idea of "God with us" to the familiar Christmas story. Matthew 1:20–23 relays this account: "An angel of the Lord appeared to him in a dream, saying, 'Joseph, son of David, do not fear to take Mary as your wife, for that which is conceived in her is from the Holy Spirit. She will bear a son, and you shall call his name Jesus, for he will save his people from their sins.' All this took place to fulfill what the Lord had spoken by the prophet [Isaiah]: 'Behold, the virgin shall conceive and bear a son, and they shall call his name Immanuel' (which means, God with us)."

Immanuel. "God with us." What *does* that phrase actually mean? It means that God is always and intentionally engaged

with his image bearers from the onset of creation right through the eventual consummation of Christ's kingdom into eternity.

But what does it have to do with parenting children with disabilities?

Let me take you to Psalm 121. It's one of my favorite psalms, perhaps because my two sons read it together for a church service years ago on a disability awareness Sunday. The passage starts out this way: "I lift up my eyes to the hills. From where does my help come? My help comes from the LORD, who made heaven and earth" (vv. 1–2).

In my experience as the mother of a twenty-nine-year-old man with Down syndrome, when it comes to parenting children with special needs, *we all need to lift up our eyes to the hills*. We need to have our vision lifted so that we can see *who* our Helper really is and *why* we need help in the first place. God. With. Us.

Gifts of Grace

Scripture gives us a beautiful overarching picture of the ways in which God is with us in the grand story from Genesis to Revelation. God's presence in each way is a gift of grace to his people. In particular, these ways are gifts of grace to those of us who are parenting children (or adult children) with disabilities.

One of the most common laments I hear from other parents of children with disabilities is about their sense of isolation. When we lack meaningful human connection and support, we can begin to forget that centrally and primarily we still always have God's abiding presence: God. With. Us. When we can "lift up [our] eyes" and see the ways in which God is with us and how those ways apply to the challenging realities before us, we find that we are the recipients of eight different gifts of grace.

We have the gift of unearned value. In the culminating act of his creation, God created male and female in his image. We are

endowed with significance and value that we do not (and cannot) earn, because God chose to be with us in the very way he designed us as his image-bearing creatures, who were meant to reflect his character into the world. “God with us” means we and our children enjoy unearned value.

We have the gift of God’s unwavering faithfulness. Even after the fall of humanity through its rebellion against God, God demonstrates his faithfulness to his chosen people throughout the Scriptures. God is a promise keeper. He is faithful to us even when we are not faithful to him.

We have the gift of an undeserved substitute. In Christ’s incarnation, the Son of God took on humanity in order to fully identify with our sufferings and to *live* a perfect *life* on our behalf and *die* a perfect *death* on our behalf. “God with us” means that he recognizes we cannot even remotely begin to live free of sin or error on our own. But we can breathe deeply. For Jesus has lived a life free of sin and error—while fully devoted to God—on our behalf. Even as we sin and stumble and make mistakes, we are free to seek after God because we have an undeserved substitute who paid the cost.

We have the gift of One who understands our sufferings. “God with us” means that we have the privilege of an undeserved substitute who also understands our sufferings. Jesus experientially knows and understands suffering in every way in which we experience it.

We are gifted with the undoing of our old nature through the Spirit. When Jesus ascended to heaven, he said to his disciples, “I am with you always, to the end of the age” (Matt. 28:20). He sent his Spirit to indwell the hearts of his disciples. The Spirit of God accomplishes the transforming work of God in us by dismantling ingrown sin and habits that dishonor God and by changing our hearts to love God and neighbor more.

We have the gift of union with Christ and his body. The indwelling of the Spirit also gives us the great gift of being in union with Christ perpetually. We are in Christ, and we are vitally connected in his body to all other believers who are in Christ too. This union with Christ and his people brings great blessing.

We have the gift of an unfailing Advocate. Upon his resurrection from the grave, Christ won the victory over sin and death and now provides the blessings of “God with us” by continually interceding before the throne of grace as the unfailing Advocate of those who put their trust in him. There is no condemnation for those who are in Christ Jesus.

We will one day delight in the gift of unending dwelling with God himself, face-to-face. At the end of time, when Christ comes again, God will make all things new. Listen to what the book of Revelation says: “And I heard a loud voice from the throne saying, ‘Behold, the dwelling place of God is with man. He will dwell with them, and they will be his people, and God himself will be with them as their God. He will wipe away every tear from their eyes, and death shall be no more, neither shall there be mourning, nor crying, nor pain anymore, for the former things have passed away’” (21:3–4).

The Journey Ahead

Will you join me on this journey of discovery? Don’t let the “overwhelm” of your family’s journey keep you from engaging with this devotional. Remember, a thirty-one-day devotional doesn’t have to be read in thirty-one consecutive days! Rather, I’d simply encourage you to create a doable pattern for reading this book (and responding to it) that doesn’t put pressure on you to complete it quickly. Although alone time in a family touched by disability can be difficult to come by, try to intentionally set aside

a few minutes throughout the week for you and God to communicate. Make a cup of tea or coffee. Pay particular attention to the Scripture passage at the top of each reading. Read and reflect on the material. Take some time to pray for insight and practical application to your life. Write what you are learning in the book at the end of each devotional. Also, consider embarking on this journey with another friend who also has a child (of any age) with disabilities. Call that mom or dad and say, “Hey! I’ve got an idea that could be really helpful to both of us!”

My prayer for you is that you will engage this book in a way that allows the Spirit to transform your heart and deepen your walk with God as you parent your child with special needs.

I lift up my eyes to the hills.

From where does my help come?

My help comes from the LORD,
who made heaven and earth.

THE GIFT OF
UNEARNED VALUE
IN GOD'S IMAGE

DAY 1

Your Child Is Different, Not Less

So God created man in his own image, in the image of God he created him; male and female he created them. (Gen. 1:27)

WHEN THE YOUNGER of my two sons was in elementary school, he had a competitive relationship with one of the neighborhood boys. My son's way of subtly getting under the other child's skin was to lean over and whisper, "Water boy," as he walked past him. *Water boy*. Why *water boy*? In team sports, is the water boy ever on the front page of the news? Is he given the most valuable player award? Does he get lifted to the shoulders of his teammates as they victoriously march off the field? No. The water boy is mostly invisible. He doesn't wear the uniform. He's less than a full-fledged team member.

As a parent of a child with disabilities, you are no doubt painfully aware that whispers of "water boy" can be directed toward your child in countless different ways. The whispers may not be loud, but they are there. In spite of the advances in legal protections on behalf of those with disabilities, the perception that they are "less than" still permeates the atmosphere. These societal whispers can begin to get under our skin.

In God's economy, however, *different* is not *less than*. In the opening chapter of Scripture, God reminds us of the simple truth that he loves diversity and has imparted value to every human being. He has created humankind to be diverse at the most fundamental level—that of male and female. Even more notable is that God creates every human being in his image. Every one of us is created with great value and an awesome responsibility: to bear God's character in the world. There is no higher form of dignity. There is no greater calling.

God doesn't make water boys. He creates image bearers: human beings blessed with the privilege of reflecting God's character through whatever God-given capacities they possess. This reality is caught more than taught. It is conveyed in how we treat others in our relationships and in how we treat our children throughout the day. When you encounter whispers of "water boy," remember that although your child may be different, he or she is not less. Your child is endowed with inherent dignity. So, as an image bearer yourself, reflect God's goodness, truth, and beauty into the world in how you respond to others and to your child.

Reflect: In what ways have you heard whispers of "water boy" directed at your child recently? Where have they come from? How have they affected you? How have they affected your child? How did you respond?

Reflect: It may surprise you to learn that the one doing the "water boy" whispering in my family was my son who has Down syndrome. In what specific ways have you seen your child engage with others that may signal that he or she needs to be reminded of his or her inherent God-given value?

Act: If you want others to see the image of God in your child, start by looking for the image of God in others today. Consider ways you can reflect God's character in your interactions. Keep a record of every encounter you have today with another person. Note to what degree you looked for the goodness, truth, and beauty of God in each individual. Describe how doing so changed the nature of your interactions with people today.

DAY 2

Every Person Has Agency

Then God said, “Let us make man in our image, after our likeness. And let them have dominion over the fish of the sea and over the birds of the heavens and over the livestock and over all the earth and over every creeping thing that creeps on the earth.” (Gen. 1:26)

UNLIKE MANY FAMILIES touched by disability who experience a revolving door of social workers throughout their lives, we were blessed for an entire decade with a gem named Keith. When Keith knocked on the door for his periodic visits, Tim, our son with Down syndrome, would perk up and say, “It’s Keith! My lawyer!” Instinctively, Tim recognized that Keith operated as an *agent* who represented him. Tim knew that Keith helped to mediate his interests in the world.

While this analogy has its limitations, in a similar way, every human being is designed to be a “Keith.” Specifically, as God’s image bearers, we are called to exercise agency—to act in ways that represent God to the world around us in whatever we do. In Genesis 1, we are commissioned to mediate God’s interests by providing for a flourishing society in the midst of a flourishing creation. We are God’s lawyers, in Tim’s terminology.

When we think of agency, however, we often have a truncated view that is more aligned with secular views of autonomy than with the idea of biblical image bearing. As God’s agents, we are called not just as individuals but as a community of interdependent people (see Eph. 4:16). In other words, we don’t bear God’s image in isolation. Agency isn’t just acting *on* the world. It is acting in concert *with* others in such a way that the world around us is influenced. When we see image-bearing agency in this way, we can more deeply appreciate the role of people—even, if not

especially, of those with profound disabilities—as having significant influence.

In his book *The Power of the Powerless*, Christopher de Vinck wrote about his brother Oliver, who had severe disabilities: “Oliver could do absolutely nothing except breathe, sleep, eat, and yet he was responsible for action, love, courage, insight.”¹ Oliver was one of God’s lawyers. He propelled God’s work in the world not by his own efforts but by the good things he drew forth from others in his limitations. You and your son or daughter with disabilities also live in community with others as agents of the living God. Live well, for his glory.

Reflect: In what areas do you see your son or daughter with disabilities as being a person of significant agency? In what ways do secular views of autonomy skew your thinking about your child’s role in image bearing?

Reflect: Consider the concept of image bearing as something we do collectively. How does seeing image bearing as a community activity make your understanding of God’s beauty come more fully alive?

Act: Practicing lawyers will often use the title “Esq.” (Esquire) after their name. This week, as you interact with your child, make a mental note to add Esq. after his or her name. Use this as a practical reminder that he or she is God’s agent in his created order. Look for ways your child actively expresses God’s character in the world and name them to yourself. Share with a friend some ways you observed your child’s needs drawing out God’s character from others around him or her—including you.

1. Christopher de Vinck, *The Power of the Powerless: A Brother’s Legacy of Love* (Grand Rapids: Zondervan, 1988), 31.

DAY 3

Nothing to Prove

Then the LORD God formed the man of dust from the ground and breathed into his nostrils the breath of life, and the man became a living creature. (Gen. 2:7)

REMEMBER, IN THIS first section we are talking about what it means to experience “God with us” through the gift of unearned value. Today’s verse hits us square between the eyes on this topic. Dust and glory. This is the stuff of humanity. Dust in the wind—and yet infused with the very breath of God. What a paradox! Yet in holding these two ideas in tension, we find the gift of unearned value. Unearned because we, in fact, are from dust. Value because we, in fact, are brought to life by God’s life. The gift of unearned value means that we not only can but also must know *who* we are and *whose* we are. We may come from the dust of the earth, but we are quickened to life by the God of the universe.

Why is this so significant? Our society communicates that our worth comes through our achievements. This can create tremendous grief for and pressure on parents of children with exceptionalities. Infused with a lingering sense of shame because our children cannot talk enough, walk enough, learn enough, produce enough, fill in the blank enough in order to compete with the achievements of those around them, a cloak of sadness settles in. But in God’s economy, value does not derive from a hierarchy of accomplishment. Instead, like everyone else on the planet, our children with disabilities are from the dust of the earth. And, like everyone else on the planet, they are also permeated with the living breath of the Creator. This means we—and our children—have *nothing to prove*.

Sometimes, people with disabilities find themselves having

to prove not only their value but also their competencies. When our son Tim was little, my mom said, “I will always assume he *can* do something until he shows me otherwise.” She presumed competence. One day, when Tim was about six years old, my mom asked him to help her to empty the dishwasher. When they had finished the task together, he cupped her face in his little hands and said, “Thank you for believing in me, Muffy.” We are dust. And we are glorious. God knows that about each of us. Do you?

Reflect: In the tension of dust and glory, where do you tend to lose your balance with the way you see your child with disabilities? Do you hyperfocus on his or her limitations, or do you tend to minimize them? How can you achieve a healthy biblical tension that honestly owns limitations and fully reflects the beauty of God-given life?

Reflect: Have you ever felt that—as a parent of a child with disabilities—you have to prove yourself to those in your community, church, or school system? Have you ever experienced the judgment and shaming of your child by others? When did that happen? How did you respond?

Act: As you work through goals you have for your child or adult child’s development and growth, remember that he or she has nothing to prove. Look for and celebrate each little accomplishment. Treat them as a firework displaying the gift of unearned value in his or her life. Print out a picture of fireworks, and place it somewhere in your home where you will see it. It will remind you to look for these expressions of God’s goodness.